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Pain Assessment in Elderly Residents with Severe Dementia – Nurses' Point of View

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<p>Background: Pain is often underrated or under-recognized in people with severe dementia for many reasons. In care unit, both register nurses and practical nurses are equally responsible for pain assessment because practical nurses work most of the time alone in shifts. Several tools have been designed to attempt pain assessment and management of pain, however they have not been routinely used in practice. So, the aim of this thesis is to understand ongoing pain assessment practices in the ward through a nurses' point of view.</p> <p>Methods: The face-to-face interview was used with seventeen nurses working in the care unit. The data were analysed with the three-step content analysis, reduction, clustering, and grouping of data. There are three research questions, namely: How do nurses experience the pain assessment procedures in the care home? How do nurses assess pain assessment in severe dementia? What factors do nurses see as a barrier to improving pain assessment among those with severe dementia? Through these questions, we tried to gain information about nurses' knowledge, experiences, others influence factors towards the pain assessment.</p> <p>Results: In the care units, practical nurses were working alone in shifts (evening, night shifts) were equally responsible in pain assessment with the register nurses. The data analysed produced eleven themes. Seven themes were developed under the nurses' approaches in pain assessment: Facial, body language and vocal as pain assessment, Physiological changes as pain indicator, non-medical approach, terminal illness as pain indicator, relatives' information as work force, knowledge on individual needs, medical history as pain assessment and the remaining four themes consisted under the factors affected in pain assessment were education role, lack of documentation, communication as a barrier in pain assessment, and pain tools in pain assessment. Behaviour and psychological approaches were not mentioned(separately) as possible pain indicators. It was considered more as a dementia process than pain related. Which was discussed under the communication barrier. Theses experience of nurses showed the lack of evidence base knowledge in present scenario about the topic. The common pain assessment was based on facial expression.</p> <p>Conclusion: It is suggested to adapt pain management using appropriate pain (s) tool to avoid a gap between knowledge (that has had already and new knowledge) and experience between staffs. The management helps to create the close intervention with the target group for a long period and makes the assessment process better.</p>	
Keywords	Nurses' view, severe dementia, pain assessment factors, pain management

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ABBREVIATIONS

WHO	World Health Organization
BPSD	Behavioural and Psychological Symptoms of Dementia
MMSE	Mini Mental State Examination
IASP	The International Association of Pain
AGS	American Geriatric Society
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
DOLOPLUS	Behavioural Pain Assessment in the Elderly
VAS	Visual Analogue Scale
PAINED	Pain Assessment in Advanced Dementia
PACSLAC	Pain Assessment Checklist for Senior with Limited Ability to Communicate

1 Introduction

People feel and experience pain in different ways while dementia progresses. Their ability to express pain becomes limited due to their speech declination (Personal social service unit, 2005). Some research shows that people with dementia may experience pain differently than people without dementia (Brown et al., 2011). But the core cause of pain in this population is musculoskeletal conditions, like arthritis, osteoporosis respiratory, urinary tract infections, injury (fractures), and pressure ulcers (bed bound) (Corbett et al., 2014).

Andrea & Barbara (2013) state that elderly pain has been untreated or undertreated which leads to serious negative impacts on health, quality of life with disturbances in sleep, cognitive impairment, social isolation, and can lead to depression. Older people are at high risk of experiencing poor pain management in elderly care due to a lack of staff and incomplete health records. The rate increases, especially with people who have dementia, because their communicating skills become low and they have less ability to recognize pain.

Dementia is not a disease; it is a syndrome which generally affects cognitive function. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, etc., with signs and symptoms dementia is categorized into three different parts: early, middle, and late stage (severe stage). A severe stage of dementia is one of total dependence and inactivity whereas memory disturbance is serious and the physical signs and symptoms become more obvious (World health organization, 2016).

The elderly with dementia is a complex challenge for the care staff to manage pain related behaviour whereas verbal expressions are limited. The national board of health and welfare has taken the starting point from the dignity and preventive care perspective in the care towards the person-centred care, multi-professional teamwork and staff training, medical treatments, and behavioural psychiatric symptoms of distribution (Karlsson, 2015).

Pain recognition and assessment is the initial step for effective pain management (Herr et al., 2011; Cunningham et al., 2010). However, research has shown nurses' uncertainty regarding pain with dementia patients (Gilmore, 2013).

In Finland, 130,000 elderly persons suffer with memory lost problems, all of whom are over 80 years old (Koski, 2014). Rapidly increasing population aged over 80 will become double by 2030. (Nieminen, 1998-1999).

Recent research (Corbett et al., 2014) has conveyed that 40-80% of dementia elderly experienced pain whereas 57% rate was from Finland. The growth in Europe's aging population demands more professionals in dementia care and urgently requires discussion in the quality of pain management (Karlsson et al., 2012).

The research mentioned that nurses informally do assess pain and are also aware of behavioural symptoms and that psychotropic medication can sometimes be used and prescribed inappropriately. They believe that pain has been undermanaged in people with advance dementia (Kaasalainen et al., 2007); whereas their pain has been under assessed and pharmacologically undertreated. Research has also shown that nurses also have different views towards pain recognition in persons with dementia and which effects in prescribing or providing analgesics occur (Andrea & Barbara, 2013).

As far as the research has been done, dementia is not the cause of pain (Brown et al., 2011). The literature review analyzed by Uusitalo and Westerholm (2010) state that understanding patient pain is vital and challenging in nursing care due to the barrier of communication disabilities. Persons self-reporting is the most reputable measurement of pain.

However, this approach to pain assessment is problematic due to the different social and cultural values, beliefs, and attitudes towards pain. So, nurses feel the lack of adequate knowledge in respect of pain management practices and it reflects, moreover, the importance of knowledge in pain assessment (Brown et al., 2011).

Recent studies show that high quality pain assessment and management processes can be achieved with both observation charts and with the documentation of pain assessment. However, research recommends nurses that should improve their knowledge in both their pain assessment and management (Chatchumni et al., 2016).

According to the policy, nurses should manage all the documentation but due to the heavy workload of caring for patients and experiencing documentation process as time consuming, nurses complete the documentation as matter of routine and not with the intention of detecting patient's pain (Chatchumni et al., 2016).

1.1 Thesis Aims

The aim of this study is to understand ongoing pain assessment practices for severe dementia residents in an elderly care home from the perspective of nurses.

1.2 Research Questions

- How do nurses experience pain assessment procedures in the care home?
- How do nurses assess pain assessment in elderly with severe dementia with their knowledge?
- What factors do nurses see as a barrier to improving pain assessment among those with severe dementia?

2 Background

2.1 Dementia from Mild to Severe

Dementia is a condition about complex symptoms which becomes progressive with time from mild to severe. It hinders elderly personalities, memory loss, loss of other functional disability like judgement, abstract thinking, and language skills. The cognitive impairment is evaluated by MMSE scores (Zwakhale et al., 2006).

According to the World Health Organization (WHO), dementia is a syndrome with comprehensive terms of number of illness, characterised by a progressive decline in cortical functions that decline numerous functions like memory, thinking, orientation, comprehension, calculation, language, and judgement. The same report has classified dementia in three stages, such as the early stage, middle stage, and late stage (severe dementia) on the bases of mental and behaviour disorders (WHO, 2016). Dementia refers brain disorders that increase lead to brain damage and disorientation of a person's individual functional capability, social relations, personality, and emotional conditions (Karlsson, 2015).

Research has found that impairment in language limits patient ability in expressing their pain which is common in severe dementia. This scenario presses us to be more knowledgeable in pain recognition in this group (Scherder, 2005).

Regardless of this complexity in symptoms, the most sub types of dementia are Alzheimer's disease, vascular dementia, and mixed of both dementia (WHO, 2011).

2.2 Severe Dementia and Pain

Pain is subjective experience which is not adequately defined, identified or measured by the observer (Burns & Mcilpatrick, 2015). The international association of pain (IASP) defines as "an unpleasant sensory and emotional experience associated with actual or potential tissue

damage, or described in terms of such damage (Hadjistavropoulos, et al., 2010). According to the evidence perception of pain, this does not disappear in patients with cognitive impaired. (Gary F. Egan, 2006). But untreated or ineffectively treated pain cause psychological symptoms such as fear, anxiety and depression. Which further affect in their(elderly) daily activities of living like mobility, appetite and sleeping (Burns &Mcilfattrick, 2015).

By the time severe dementia has progressed, patients' abilities to express about their feelings about pain and others becomes dramatically low or none. Their behaviour gets more aggressive or vulnerable, but these behaviours can be indicated as a self-protection mechanism because they cannot articulate their pain. (Zwakhale et al.,2006).

Physiological indicators are not always enough to represent as a pain behaviour due to the facts of others health related issues like distress (Hadjistavropoulos, 2001).

But research on the base of multi-dimensional tools was evaluated by combining physiological and behavioural indicators which been reported as appropriate comfort measures. (Davies, 2004).

Confusion and equivocalness (Gilmore et al., 2013) behaviour symptoms can lead a clinician to purposely delay pain management or even lead to no treatment at all. It becomes even more challenging to detect and sense pain due to the perceived difficulty connecting with dementia (Brorson et al., 2014).

Elderly with moderate cognitive impairment can report the intensity of pain where non-communicative elderly pain assessment primarily relies on observational scales (Scherder et al., 2005).

In one pain assessment experiment research, has showed that autonomic responses like blood pressure is high in Alzheimer disease than in the elderly with their cognition intact. This means that high blood pressure indicates high levels of pain intensity and vice versa. But it is still not an accurate measurement for the perceived intensity of pain (Scherder et al., 2005).

As AGS states, there are a multiple number of sources that cause pain in elders. These include: degenerative joint disease, fractures, urinary retention, pressure ulcers, neuropathic pain, improper positioning, cancer pain, contracture, constipation, oral dental sources, sleep disturbances, malnutrition, depression and anxiety, challenging behaviour, polypharmacy,

etc. (Shah et al., 2016). Most elderly with dementia (Somes et al., 2013) are inclined to infections, fractures, pressure ulcers, constipation, and other painful conditions.

2.3 Approaches in Pain Assessment

2.3.1 Behavioural Approach

Pain behaviour is extremely limited or not yet researched which makes clinicians difficult to recognize it and even mistreat pain symptoms. Familiarization with the demented patient is a suitable approach in the assessment of pain. (Corbett et al., 2014).

Due to the neuropathological changes, cognitive impairment in the elderly might have difficulties expressing their pain. In addition to pain expression or assessment among cognitively impaired elderly, they may also have strongly exposed their bodily/ facial expressions as a pain indicator (Shah et al., 2016). The elderly emotional and behavioural observation are considered to conduct the pain assessment as they cannot self-report. (Monroe et al., 2012).

About 90% of people with Alzheimer's may expose at least one Behavioural and Psychological Symptoms of Dementia (BPSD) during the disease (Liperoti et al., 2008). Due to the relationship between pain and neuropsychiatric symptoms (Ahn et al., 2013; Tosato et al., 2012). It has been suggested for further research to investigate the BPSD symptoms to find the reason behind why there might be pain (Ahn et al., 2015). But some research shows pain is the major key for the development of BPSD (Cohen et al., 2009).

Inadequately cared BPSD symptoms might lead to increased falls and injuries. Even though it is huge challenge to understand BPSD alone and under consideration with multi-factorial elements that are connected to the setting and existence of physical illnesses and pharmaceutical products (Karlsson, 2015).

Due to the communication deficiency of an elderly patients, pain problems more likely unrecognized or undertreated which increases the risk of aggressive behaviour as well as difficulty making physical adjustment to manage pain like lifting the limb (Martin et al., 2005).

In general, the condition of delirium is another component that hinders the pain assessment process due to the cause of the fluctuation in mental status. It has found to be in co-relation between delirium and pain. Baseline assessment of patient behaviour and observation by the well-known care giver can be the best tool of recognizing behaviour (Buffum, 2007).

2.3.2 Observational Approach

The study suggests that social withdrawal and depression symptoms should be considered as possible indicators of pain (McCabe et al., 2006; Onder et al., 2005). Those symptoms might be taken as a progressive dementia behaviour rather than an indication of pain (Kunz et al., 2009; Karlsson, 2015).

The self-report became limited due to the loss of communication ability and abstract thinking in later stages of dementia (advance dementia). The numbers of pain assessment scales have been developed to address pain through observational measures. This includes facial expression, vocalization, and body movements. (Corbett et al., 2012, Corbett. et al., 2014).

When assessing pain in care, we should be aware of the symptoms related to pain and delirium because both symptoms resemble each other. They include moaning and acting aggressively, which is more often included as indicators of pain in observational measurement. (Hadjistavropoulos et al., 2010).

The behavioural signs are not easy to identify and it must be occurred several times and be observed by the same caregiver to recognize symptoms as pain (McAuliffe et al., 2009). However, one way of assessing pain is observing behaviour that signals the presence of pain like grimacing, guarding, rubbing the affected area, changes of mood like frustration, impatience, depression, other behaviour-like sleep patterns, eating patterns, etc. (Martin et al., 2005).

Additionally, observational pain assessment also includes recognizing pain avoidance bodily movements or positions to minimize the pain (Corbett et al., 2014). The progressive cognitive and functional decline in elderly dementia, the observational pain cues become more essential and yet more ambiguous (Lichtner et al., 2016). But the fact is, bodily movement becomes none in severe motor impairment like Parkinson's disease dementia, which leads to an incorrect pain assessment or inaccuracy in pain detecting process (Corbett et al., 2014).

2.3.3 Medical Approach

The main source of pain in the elderly is associated with their chronic health disorder like arthritis, peripheral vascular disease, cancer, and other surgical procedures. It leads to numerical medical conditions like depression, sleep disturbances, aggressiveness, and

anxiety that might be crucial in the treatment of pain assessment in acute clinical (Brown, 2011).

Furthermore, the declination of mental state is due to the pain and not an intake of analgesic, as some have believed. More often, their behaviour is associated with symptoms like verbal and physical aggressiveness and agitation, which increases the patient's distress and becomes a huge challenge for the care provider. Therefore, patients exposing (problematic) challenging behaviour due to the cause of inadequately treated pain are often cured by antipsychotic analgesia (Brown, 2011). The American Society for Pain Management Nursing's Task Force on pain assessment has mentioned that if we believe that the elderly is suspected to be in pain, a clinician can consider the short period of analgesic trial and observe the patient on how their behaviour has changed before and after medication (Horgas, 2012).

Due to the lack of self-reporting, some could believe that the cognitively impaired experience less pain or no pain at all and that some caregivers can see opioids medication as an addiction (Corbett et al., 2014). Some elderly with dementia are sometimes given neuroleptic medication when underlying causes of their behaviour is pain. In such a case, pain may be unrecognized, untreated, whereby the patient may suffer unnecessarily (Martin et al., 2005).

As stated in the literature of psychosis, hallucination and delusion are not referred to as pain symptoms. These two symptoms are treated with antipsychotic medications. As of now, antipsychotics drugs have little efficacy, with many side effects which can decline cognitive functions, cause parkinsonism, stroke, and even death. Only the drug risperidone has a consistency nature if it is used for about twelve weeks (Corbett et al., 2014).

Several studies have mentioned using sedative drugs in the treatment of sleep disturbance. This might cover the main symptoms of pain in a cognitively severe elderly and increase the risk of polypharmacy. The appropriate assessment tool would be more important in proper and immediate actions (Corbett et al. 2014).

According to the American Geriatric Society (AGS) pharmacological guidelines, paracetamol is the first line of the treatment approach in pain in dementia. The benefit or adverse effects of using NSAIDs, anticonvulsants, antidepressants, and other analgesics must be investigated further (Corbett, 2012). The current situation of quality treatment and management of pain in dementia lack in clinical practices. Over 50% of older people gets analgesics, but studies have shown the use of paracetamol (benign drug) among dementia

at 46% whereas 25% of cognitively impaired people use paracetamol. This shows that dementia in the elderly gets less opioids (Corbett et al., 2014).

2.3.4 Social Approach

As the World Alzheimer's Report statistics, have stated, dementia is a global public health challenge that demands enormous professional attention and services as well as the support from relatives (Karlsson, 2015).

Family members or consistent caregivers can provide valuable insight into the patient's customary behaviours or changes in behaviours. Those changes in behaviour may include crying, restless, and so on, and can be a sign of pain (Horgas, 2012).

However, there are no definite rules for pain assessment, so using relatives or caregivers as a pain assessment tool to know the elderly better is important (Horgas, 2012).

The research showed that trust and familiarity of caregivers with the elderly with dementia are important factors to communicate their pain (Lichtner, 2016).

Relatives, visitors, carers are information sources in pain recognition, assessment, and management of pain and can act as a messenger on behalf of the patient with dementia (Lichtner, 2016). As suggested in research, these individuals could be the hidden workforce (Fry et al., 2015).

2.4 Pain Assessment Tools

Numerous pain assessment tools have been developed lately and it is still in developing needs. Generally, pain assessment scales are categorised into self-rating scales and observed-rated scales of behavioural pain indicators (Lukas et al., 2013). Although reports have said that despite several tools in recent development, their clinical test and evaluation have still been limited. (Herr et al., 2011). But for the better pain assessment it requires pain assessment tools that is designed for the cognitively impaired one (Burns & McIlpatrick, 2015).

There have been guidelines for assessment and measurement of pain in people with cognitive impairment (Cunningham et al. 2010; Herr et al., 2011) but there are still no appropriate tools to measure pain among those with severe dementia (Lints et al., 2012; Herr et al., 2011).

Pain has been conceptualized as a multi-dimensional sensation with psychological and emotional effects (Gagliese & Melzack, 2005). Considering this, one dimensional instruments would not be appropriate for the right pain management with severe dementia (Gibson et al., 2012). Pain assessment is the interdisciplinary evaluation that relies on health care staff's subjective impression (Dobbs et al., 2014).

In Karlsson (2015), research has stated that individuals with mild to moderate dementia are able to express their pain as self-reporting, but there is a higher chance of involving psychosocial indicators rather than pain. The choice of appropriate tools is an important task and is used to avoid underdetermining the pain of an individual (Apinis et al., 2014; Lukas et al., 2013a). But research has so far found and suggested that observational scales must be used for those people whose pain cannot be conducted via self-assessment (Karlsson, 2015).

The research has compared PAINAD tool with the discomfort scale and two visual analogue scale (discomfort and pain) by trained experts such as clinicians in the development study. Results have shown that both PAINAD and DS-DAT (Discomfort Scale-Dementia of Alzheimer Type) were co-related, but still requires further research, while the research was conducted in limited sources (Warden, V. et al 2003).

There is enormous research in the field of pain assessment methodology which is under the observation checklist to record specific pain behaviour. The articulation of pain differs between cognitively poor patients (those with severe dementia) and cognitively intact patients, despite their equal pain related conditions. The same report has shown that cognitively intact patients who self-report for pain get three times more pain medication than cognitively impaired ones. (Hadjistavropoulos et al., 2010). However, the self-report for pain is most valid and reliable information although it is not possible for cognitively impaired ones. Whereas clinical observation of pain is needed under many perspectives (Hadjistavropoulos et al., 2010).

2.4.1 Doloplus-2

Doloplus-2 covers 5 out of the six recommended domains by the AGS. The Doloplus-2 score does not represent one's experience with pain at a specific moment, but reflects on the progression of experienced pain verbalizations and vocalizations, changes in activity patterns and routines, changes in interpersonal interactions, facial expressions, and body movements. Only 1-5% of individuals have been tested by the DOLOPLUS tool with VAS

tool and DOLOPLUS, which measured more sensitivity. Some items seem difficult to interpret by the users. Clinical utility should be further tested in large areas with nonverbal cognitively impaired elderly patients (Hadjistavropoulos et al., 2010). But research has shown that with Doloplus-2 scores, 20-30% of items overlapped with delirium, so it needs to be given more attention while using these tools, considering pain can cause delirium (Hadjistavropoulos et al., 2010).

2.4.2 The PAINAD

The PAINAD clearly covers three of the six AGS-recommended pain assessment domains like body movements, verbalizations and vocalizations, and facial expressions. The additional items of the tool focus on breathing patterns and consolability which is also AGS recommended domain of interpersonal interaction (Hadjistavropoulos et al., 2010).

The pain assessment with PAINAD takes less than a five minute (Horgas et al., 2008). It has shown the moderate correlations with other measures of pain behaviour (Warden et al., 2003). whereas research has shown its ability to discriminate between pain-related and non-pain related situations (DeWaters et al., 2008).

2.4.3 Abbey Pain Scale

The ABBEY PAIN SCALE items on this scale cover five of the six AGS-recommended domains, like facial expressions, verbalizations and vocalizations, changes in activity patterns and routines, and body movements (Hadjistavropoulos et al., 2010).

Moreover, it has been evaluated in several countries such as in Japan, Germany, Hong Kong, Netherlands, and Australia and has satisfactory psychometric qualities and utility in clinical practices (Lukas et al., 2013; Neville et al., 2014). The scale may be a better choice if it is used occasionally and has a lower level of nursing qualifications (Neville, 2014). However, the Abbey Pain scale still lacks a scientific method for language translation (Karlsson, 2015).

2.4.4 The PACSLAC

The PACSLAC covers all six of the AGS-recommended pain-assessment domains. It contains a 60-item checklist of the most comprehensive behavioural observational tools. The tool has many sub-categories but it tends to be more reliable when total scores is interpreted than sub-scales scores.

However, it can be completed in five minutes after minimal training. Additionally, this tool has stated better psychometric properties and clinical utility. The regular use of the tool in pain assessment helps to reduce stress and burnout level. (Hadjistavropoulos et al., 2010).

2.5 Challenges/Barriers in Pain Assessment

The research has showed that the lack of training and education has been proven as a poor management and assessment of pain in elderly with dementia. Research has also found a gap between understanding and knowledge of pain in dementia among nurses and inaccurate myths concerning pain relief (Ghandehari et al., 2013; Coker et al., 2010). Although all education has not been effective, it is believed to be a main root of many barriers (Jones et al., 2004). Above all, 75% of nursing homes did not use any kind of standardised pain / assessment tool (Allcock et al., 2002).

The caregivers are reluctant to use opioids, which is another barrier in pain assessment (Rantala, 2014) and by 37% of physicians are reluctant to prescribe adequate pain relief because of the fear of overmedication and 1% of physicians identified their own reluctance to give pain medication to older patients (Coker et al., 2010).

Research has indicated that it is understandable for nurses to have a fear of overmedicating patients. This is because geriatric patients often have multiple diagnoses with several drugs in their system at same time. This may lead elderly patients to experiencing adverse side effects and drug interaction (Rantala, 2014; Weissman, 1999). The lack of knowledge and skills of caregivers also determine the weak assessment of pain (Innis et al., 2004). Except several systems related barrier, lack of optimal team functions, communication, insufficient time (Fox et al., 2004), these indicate a need of actual administration in pain management (Gordon et al., 2005).

The training module of the best clinical practice on pain assessment in dementia was developed by taking into consideration collaborative team work, open communication, person centred care, staff information, and training (Wall et al., 2012).

Most indicators must be observed and documented but a nurse's lack of compliance with recording pain on every shift has been a challenging process. In a morning shift the observation and record keeping happens. Most respondents reported tools were more complex and time consuming and had left to be completed (Davies, 2004). Another study

found that the main barrier in pain assessment among hip fracture dementia patients were cognitively impaired ones (Rantala, 2014).

The overlapping symptom with pain related behaviour and BPSD are another critical factor in the decision-making process which complicates treatment. Meanwhile, the location and intensity of pain is another current pain assessment challenges factors (Corbett et al., 2014).

3 Methods

3.1 Study Design

The study was conducted using a qualitative method. Face-to-face interview discussion was chosen for exploring the pain assessment in elderly residents with severe dementia through nurse's point of view. Face-to-face discussion viewed as a suitable to help to courage each participant to share their knowledge individually and free with stress. As a second set of data, group discussions were held.

During the group discussion, same questionnaires from face-to-face interview process were presented. Participants were free to share their views/ thoughts if they have had any (left) from the previous face- to -face interview section.

Participants characteristic

In the data collections, the majority of participants were Practical nurses and two Registered nurses. All the interviewees had a permanent position in the ward (except one nurse who was a temporary worker but had been working long in unit). Duration of working in the same ward for the participants varied from 3 months to 10 years' period. The newly graduated staff were also interviewed to understand their current knowledge on pain assessment among elderly people with severe dementia.

In a group discussion as a second data set, there were nine participants (were same interviewees from face-to-face interview process).

However, their obtained knowledge with respect to pain assessment tools for those with severe dementia were limited. However, every participant's knowledge on VAS scales (visual analogue scales) were similar and familiarized with.

Morning shift	Evening shift	Night shift	Weekend
5 or 4 (1RN is obligatory)	3PN	1 PN in each ward.	4/3 (PN)
RN (Registered nurse) PN (Practical nurse)			

Figure 1. The flow of staff

The chart above shows the number of practical nurses were predominately high in comparison with registered nurses in each shift.

As a reminder, Practical nurses were responsible for administering the prescribed pain medication as well writing the whole report and conveying the report to Registered nurses.

3.2 Ethical Consideration

When conducting the research, it is important to consider ethics, that guides researcher how to proceed research without vandalizing ethical boundaries. Uwe Flick has stated four ethical principles, like autonomy, that respects every participant's opinions. Beneficence is also one of Flick's principles, where research provides positive and beneficial results to mankind, non- maleficence or avoid participants harm (Flick, 2011). The data was collected after receiving a written permission (Appendix 3) by the responsible administrative institution of the company. The interviewees participation was voluntary. The verbal consent was adapted from interviewees during the interview process and were informed that the data would be treated confidentially.

3.3 Data Collection

The study was performed at a residential home for people with dementia (mild to severe) as well as those who are not capable of living on their own at their home. The research has, however, focused on residents with severe dementia and their pain assessment from a nursing point of view.

The face-to-face interviews were conducted using the semi-structured questionnaires. The interview process started with the introduction of the topic and notified of interviewees to focus on pain assessment among those with severe dementia. The face-to-face interview started with following open ended- questions: (I) How do you recognize pain in patients (elderly residents) with severe dementia? (ii) Do you use any pain assessment tools? Describe what you use. (ii) Do you use when you need, or occasionally? (iv) If not, why do

you not use? (v) Are there any obstacles in pain assessment among severe dementia patients? Or (vi) what are the other factors that affects in pain assessment among severe dementia? These open-ended questions were followed others specific questions or probing statements like new patients.....? poor documents then? Do you communicate with relatives.....? In that case how you assess? No facial expression so.... how?. she has always been saying what do you think about his/her pain then? What do you mean education even can't help, could you clear a bit more? Do you think education could help? Did you mean using randomly....? What do you mean music could.....? in that case could you tell me little more through example? The recorded interview was between 15 -30 minutes. The conversations were tape-recorded.

Acquiescence of participants were positive. To conduct the interview there was not any time reserved. Rather, interviews were conducted during nurses' spare time. It gave more flexibility, openness, and less stress between interviewer and interviewee.

The qualitative data with a semi-structure interview gave interviewees the opportunity to not only to answer the questions but also to express their open thoughts about the topic in their own words.

The provisional target was to interview all the caregivers of the ward (n=22). However, 17 of 22 caregivers were participated in the first interview process. In a group discussion as a second data, nine participants were participated. Same questionnaires were presented. Group emphasized in saying it is hard to recognize whether they are having pain or not when they (elderly) cannot communicate with nurses about their needs and worries. One participant said, "I remember what I have said in the interview (face-to-face interview), I don't think I have anything to add". Otherwise, through group discussion, it did not produce any additional views or knowledge/ experience rather enhanced trustworthiness for the collected data.

3.4 Data Analysis

The tape-recorded interviews were transcribed verbatim. The data was analysed by qualitative content analysis with semi structural questionnaire. That provides an overview of important concepts such as meaning unit, condensation, abstraction, content area, code, category area and theme. This enlighten the research procedure and suggest achieving trustworthiness throughout the steps of the research procedure (Graneheim & Lundman, 2004). The written texts were read through several times in order to get an understanding

of the transcripts. Original and simplified expressions were written down. Nurses' views on pain assessment among severe dementia were extracted into several meaning unit. Secondly aggregate the list of the meaning units into condensed meaning units. Then those condensed meaning unit were grouped into underline meaning unit that covers their original meanings. Later those meaning units were abstracted into sub-themes. Without diminishing the meaning of every unit, it was extracted into themes. The data from the group discussion did not produce any new views or thoughts. Examples of the meaning unit, condensed meaning unit, sub-themes and themes are presented in figure 2.

Meaning unit	Condensed meaning unit description close to the text	Condensed meaning unit interpretation of the underlying meaning	Sub-theme	Theme
I don't think education can solve pain assessment. Anyways, it's hard to recognize pain in non-verbal patients. Pain can only be identified by their subjective views.	<ul style="list-style-type: none"> • Education can't solve pain assessment • Hard to recognize in non-verbal residents • Applies subjective views 	<ul style="list-style-type: none"> • Pain is an individual experience • Education alone can't solve • Communication issue being subjective views 	Education alone not a solution in pain assessment of non-verbal patients.	Education role in pain assessment
I never had topic related education during my work experience (Majority of participants experienced). I believe that lack of knowledge on pain assessment makes difficult to recognize pain among severe Dementia.	<ul style="list-style-type: none"> • Lack of knowledge on pain assessment • Difficulty in recognition of pain 	<ul style="list-style-type: none"> • Inadequate knowledge / education in pain assessment. • Perception of pain 	Lack of education on pain assessment.	
If patients do not react in any situation like during care, no facial expression, no gestures. Especially in the terminal care (in a condition, like if they have cancer, or another chronic disease) strong opioids should be given just to make sure that person is not suffering from pain.	<ul style="list-style-type: none"> • Severe dementia elderly with terminal diseases hardly have facial or bodily expression, so offering pain medication could be humane. 	<ul style="list-style-type: none"> • Lack of bodily expression • Requirement of frequent pain medication 	Chronic disease with the lack of bodily expression required frequent pain medication.	Terminally ill patient with chronic disease routinely need pain medication
I believe that severe dementia patients should get pain medication sensitively (when they are dying)	<ul style="list-style-type: none"> • Severe elderly people with dementia should get pain medication <u>herkästi</u>. 	<ul style="list-style-type: none"> • Need of regular medication 	Regular pain medication	

Figure 2. Example of qualitative content analysis on pain assessment among severe dementia through nurses' point of view.

3.5 Trustworthiness

The anonymity of collected data was preserved by interviewing under their experience and knowledge not with their name. The confidentiality was secured that only the researcher has access to the collected data. Electronically stored data were disposed after final analysing.

As Saunders (2009) stated, being familiarization with the institute helps to achieve the validity and reliability of the research process overall. So, the researcher chose this topic after

realizing its importance in their own work place, where the researcher has worked for many years. The ward manager approved this topic after discussing with the researcher first. It will help nursing staff in general to realize their current understanding and views towards the topic. This research is important for elderly wellbeing with severe dementia as well as nursing staff, and will help nurses and health practitioners realize present conditions and help the organization make movements for an improvement.

The four elements credibility, transferability, dependability and confirmability was applied for ensuring trustworthiness of qualitative research (Shenton, A, 2004).

The credibility was ensured by the same participation attending from first data collection (face-to-face interview) process to second data collection as group discussion. There were six open ended questions which followed later with more specific questions with probing statements. The group discussion encouraged participants to share and discuss more views or experience/knowledge on pain assessment. Contrary to the researcher's expectation, there was no significant additional information that could add more to the analysis part. The research included participants' years of work experience, occupation, education level, each participant's responsibility/condition at the work. Ensuring that readers (who) had a clear understanding of the participants. These characteristics allows other researchers in future to use the similar research approach. Group discussion enhances the same views and thoughts about the topic. Which ensure dependability of the collected data.

Confirmability was the last elements to conform the trustworthiness of the research. It was secured by the two processes. First, the group discussion as a second data enhances the same views over the first data from the face-to-face interview. Then it was established to keep original meaning of the data through raw data, data reduction to data analysis process. In addition, the research aim was secured by reading several times of its results.

4 Results

The data analysis resulted in eleven themes, which address nurses' views on pain assessment among severe dementia in the unit. The themes are; Facial expression, body language and vocals as pain assessment; physiological changes as pain indicator; non-medical approach: terminal illness as pain indicator: relatives' information as work force: knowledge on individual needs: medical history as pain assessment were under the nurses' approaches in pain assessment. Similarly, other themes such as role of education, lack of documentation, communication as a barrier in pain assessment, and tools in pain assessment, which

were included under the factors that hinder pain assessment.

4.1 Nurses' Approaches in Pain Assessment

4.1.1 Facial Expression, Body Language and Vocals

Facial expressions and body language were two common ways of assessing pain among severe dementia in the elderly. Every participant has common views and understandings on this. Along with this, patient's vocal was another pain indicator in assessing pain. Some participants' views are as below:

"If elderly can't express in word, their facial expression, body languages and vocal (sounds of pain like "auch!") could be the sign of indicating pain".

One participant shared a view like "sadness in facial expression, increasing of forehead wrinkles, sensitiveness to touch, feeling uncomfortable to sit (refusing to sit); these indicators show that they might have pain".

One newly graduated nurse said facial and body language may be common things that we focus on in pain assessment.

The participants mentioned similar views, saying that mostly with the bed patients, these facial expressions, body language and vocal signs could be easy to detect. Because their activities are less and easy to focus. Like participants mentioned "mostly during the care when we lift the patient from one place to another, bodily language could be one that indicates pain" and another participant's view was that "some elderly grab things tight when nurses are taking care of them".

4.1.2 Physiological Changes as Pain Indicator

The only two participants shared these views as a pain indicator during the process. Physiological changes like blood pressure and temperature were two factors that the nurses used to connect with pain, especially, when elderly was in terminal care or a patient's general condition of health was in a bad shape. Another participant said that along with the high blood pressure, sweating could be sign of pain". But most of the participants did not mention these factors during the interview process.

One participant mentioned those measurements give a kind of signal to staff when a person is having pain. One said: "he gets opioids for his pain, and if the temperature rises I basically

think this person is still having pain, so I think about giving another dose.... it's common that during the last stages of life that there are no revealing facial expressions, therefore this method is one way to evaluate a person's condition..."

In addition, the sign of high blood pressure and temperature was referred as a sign of pain indicator. Otherwise, most of the nurses measured the vital sign as a regular check-up like once in a month or more often if the elderly residents were feeling sick. The random measurement with high blood pressure was not considered as a sign of pain but the nurses kept measuring it for a couple of days.

But in practice, it was more like pain assessment could have remained undetected based on vital signs (more often) because of its different interpretation. The possibility of physiological pain assessment depended on elderly's visible wounds, fractures, long-term illness and other diagnoses etc. The participant mentioned "if elderly has highly abnormal blood pressure and there are no heart diseases in medical history, high blood pressure could be the cause of pain (usually)".

Lastly, one participant mentioned that when elderly has some physical disabilities (due to the temporary reason (fracture, joint problem, wound), they become more sensitive while we touch their painful part of the body. For example, "when I touch his hands he cries "ouch!". In normal case, he would not have done it".

4.1.3 Non-Medical Approach

The three participants mentioned about using non-medical approach in their work depending on the situation. At least they said that it had helped.

They had thought that music and massage could be considered as a pain relief method. They believed that it helped them to calm down through general care like massaging and communicating, listening to music.

"She likes (nurses' assumption) when I am near and give her massage, then she becomes calm, she likes being talked before starting any other care procedures... It is time consuming, when you are fewer staff and many works to finish then you intentionally or unintentionally rush to do things, then they get panicked, and start to throw things or even start kicking...so..."

One participant mentioned: "during the night, when a patient gets restless, I offer a glass of

water, then they go to sleep afterwards.” Being a part of regular staff, knowing individuals’ needs and of course the nurses’ own skills seem important in this kind of approach. These non-medical approaches always come first in mind before the offering of any medication. Thus, non-medical approach regarded as a prior (first) approach if they (nurses) don’t find or see any clear signs of physiological changes (wounds, high level of vital signs....) and medical history of pain medication in elderly’s documentation. But one participant mentioned that they always tried non- medical approaches first. Furthermore, if it did not help then they would think of other choices like offering pain medication. Of course, they mentioned “depending on the situation”. It was clarified as an example like “dementia elderly with having mild pain just nurses’ presence and mood distraction towards nice things can help to relieve pain”.

However, at least one other participant mentioned precaution as a non-medical approach method to avoid pain in bed patient. But not having enough resources to prevent sore wounds was another problem in the unit. The participant realized that bedrest patients (elderly) were under higher risk to feel pain than those who were physically active. In fact, it was not well noticed until they developed a wound. They also emphasized it was their responsibility to avoid a wound from developing in the first place.

4.1.4 Terminal Illness and Pain Assessment

Six participants mentioned during terminal illness (care) pain assessment of elderly dementia become crucial. Two participants said, “pain detection is easy with the hospice care patients (elderly) because nurses spend more time with them and they are bed patients”.

The participant believed that during the last stage of terminal care most patients have no facial expression, nor body language. In those situations, nurses should make their own evaluation or assume that they (elderly) are having pain. During this kind of condition, a participant stated that “It’s better to give pain medication to prevent severe pain...” Other participant shared similar view but in a little different way: “in terminal stage it’s important to make elderly feel more secure and painless as much as possible even if there is some sign of pain”.

One participant differentiated even more precisely in what condition terminally ill should get the pain medication. “You know [...] breast cancer, and it appears now as a wound in it, it is no doubt painful and her overall condition has changed since then. She is tired and doesn’t eat well. She is now more needs [bed rest]. before she could sit for breakfast and lunch but

not anymore, she is suffering from pain but doesn't have strength to show it physically nor with speech. Nurses can only imagine that she has pain. So "offering pain medication without exact signs and symptoms of pain is humane in a condition like this."

Furthermore, terminal illness mostly diagnosed with cancer (in some cases even multiple fractures) were considered the possibility of having pain (or even severe pain) than other elderly who did not have any of these. However, during the terminal care nurses (two participants) felt pain medication, especially strong opioids, should be given without hesitating if the elderly are in dying state. Because nurses felt that there is no need/point to consider any side effects in this stage.

Lastly it was also discussed that nurses' interpretation varies as well as patients' persistent for pain varies as well. In this case one of the earlier participants shared view like "she always says auch! auch! It's painful....., but some others (elderly) never complain even if there is a possibility for pain". This view is supported by another participant's view: elderly might say they are not having pain but nurses' can feel (assume) that elderly is actually having pain."

4.1.5 Relatives Information as a Work Force

The limited participants experienced that using relative's information had been helpful in many situations when they could share it. But they had faced difficulties in pain assessment when new elderly with severe dementia come to home care without any relatives (or not having relatives at all) although different participants had different views on this. Some took this as an important source, whereas some others even didn't mention where few of them were not able to ask information from relatives. In fact, one participant shared their experiences like this:

"Sometimes relatives themselves won't give information due to their personal affairs, there might be some physical violence behind, which they don't want them (staff) to know" or maybe "they fear how staff will take it".

Second participant said that if the relatives of an elderly had had been taking care of them long enough, and know them better, it is good to ask about nature and behavior towards the pain they react. But participant believed that hardly they could know about it. But other two participants have positive thoughts about sharing information with the relatives, as it could be helpful: "It is always better to ask their relatives".

However, one participant shared his thoughts that it is a difficult situation if elderly shifted to the care home directly from their own residence without any proper medical diagnoses. That might take several months to get to know them (elderly). During those period, elderly might get wrong diagnoses (just on the base of their behavior nature). So, a family member could give hints or some information about pain related behavior.

4.1.6 Knowledge on Individual's (Elderly)

Most of the participants expressed that “working for a long time in the ward helped nursing staff to understand elderly’s pain related behavior more”. one participant said that if there are temporary staff in shift, they usually don’t know what is normal behavior for elderly. Their (elderly) behavior attitudes can be misjudged or remain unjudged or judged as normal behavior of advanced dementia.

“I have noticed, when she/he has need for the toiletbecome restless... more often difficult to manage with one nurse... but if we notice earlier and help There are no problems afterwards but if we notice a bit late ... then we need to have two nurses.....but if there are new persons taking care..... they might not know what that attitude (behavior) is indicating.... Ok I am telling I am always but it is how I have experienced...” So, this emphasized that knowing the elderly in advance greatly supports pain assessment.

But two participants shared their experiences that it’s not always (being a long-term care giver) easy to understand elderly’s’ behavior. For example: she had a habit of saying that her leg hurts while she walked (there was no sign or symptoms about fracture or wound or anything) yet she walked while nurses were not around. One day they saw a swollen ankle. This might have had taken as her habit of only saying it hurts, if nurses have had not noticed the swollen ankle afterwards”.

One participant had shared feelings about taking care (daily care process) of elderly alone is much more better than with a pair. He/she believed that being in a pair caused insecure feelings and elderly started to behave aggressively. So, participant concluded that knowing elderly’s behavior/needs helps to minimize those vulnerable acts (kicking, throwing) which could have been misjudged as psychological behavior or even could have been referred as pain behavior. As in:

“Sometimes a patient becomes panicked if there are too many nurses working at the same time. [They become] aggressive, so better be alone with the patient, and talk with them all

the time, gently, friendly.”

The participant also believed that knowing elderly for long had been helpful to detect whether it is a pain related behavior or just a normal habit. It was mentioned that caregivers should concentrate more towards elderly during the care, rather than distracting own moods and communication in another task. The participant believed that caregiver should communicate friendly even if they (elderly) don't have a communication skill. In his/her opinion when caregiver talks with them, they feel secure in some ways.

4.1.7 Medical History as Pain Assessment

One experienced nurse mentioned that medical history of elderly could assist nurses to assess their pain behavior, for example:

“When you know, patient has some diagnoses like cancer or chronic disease then it's easy to reflect their odd behavior to the pain because normally you know how they behave.”

Another participant notifies: “sometimes elderly come with no or lack of medical report that time you don't know what exactly... [T]hen we don't know what to do... their aggressive behavior is more related to progressive dementia.”

The participants have reported that sometimes medical history could not give all the picture of elderly's needs of pain medication. It could be a time to reconsider the needs or even some other choices for the pain care. The participant pointed that medication (pain killer) list should be updated (better reviewed regularly). So that we don't go for the same dose, if pain is not severe or vice versa.

4.2 Factors that Hinder the Pain Assessment

4.2.1 Education's Role in Pain Assessment

Despite one participant's experience on education's role being not considered helpful or important, the rest of the participants promoted the important role of education on better pain assessment among elderly with severe dementia. They emphasized even more that related training in pain assessing and managing among severe dementia was needed despite its cognitive impairment. Newly graduated practical nurses also found education as an important factor for better pain assessment in care homes. However, the fact was they seemed unknown about the choices of the pain tools except VAS tool.

A single participant's view was like this: "Even education can't help in pain assessment because it is a subjective experience, it is hard to recognize and hard to measure".

Most of the participants experienced that pain is a subjective matter of fact; its interpretation varies from person to person. "Different people measure pain differently", "[one's] own experience and nature affects pain assessment".

The knowledge on related topics, whether it is from work experience or one's own knowledge, had a positive effect in pain assessment.

Without any hesitation, however, some of them shared their experience on how difficult it is to distinguish between pain-related behavior and other normal behavior of dementia. So, they regarded pain assessing among severe dementia as a complex phenomenon. The expression of nurses below was so impressive:

"Sometimes we give/ try (doctors prescribed medication on the base of nurse's description) with pain medication but person's (demented elderly) attitude (aggressiveness, restlessness etc.) remains [the] same. In other ways, "we give/ try with psychotic medication but person's condition doesn't change. So, knowing person's nature/habit/behavior along with the education about pain assessment is required.

One participant mentioned that those who have more experience could perform better in pain assessment. However, it was also emphasized that updated knowledge on the topic along with experience is highly needed. The experienced participant shared couple views like these:

"Experience gives nurses confidence about pain and courage to take the voice to the physician and ask for the pain medication".

"It is important to know what are the medicine's side effects and what needs to be checked after taking it". The participant mentioned that "pain patches is not suitable for everyone, it develops some weakness in legs and confusion".

"If ones(elderly) pain does not get treated in time, their restlessness (due to the cause of pain) drives the other elderly even more restless in unit".

The participant believed that if the nurses have enough knowledge and experiences, using this medication helped with working life. one said:

“Long time ago I also hesitated to give strong opioids when I did not have experience, and now people (nurses) hesitate if they don’t have experience in this”.

The person’s experience effects in that way that even elderly is still having pain. Due to the lack of knowledge/experience, it remained uncured/unnoticed. Like: “some can think that strong pain medication can’t be given any more”.

At last, one participant shared his/her opinion that “we should have a broad pain treatment possibilities not just with some Panadol or opioids. There must be something new like non - medical approaches (was not said what exactly) out there but we are stuck on using same methods and techniques”.

4.2.2 Lack of Documentation Effects Pain Assessment

Some of the participants described documentation was important in pain assessment process. One participant said that the doctor visits the unit once in a week and checked elderly’s document with nurses before any prescription. So, the participant believed daily reports in every shift became crucial in the end with respect to prescribing pain medication.

The participant believed that documentation give the picture of elderly’s behaviors and attitudes. It shows the elderly’s movement (walk), their feelings during every shift. It also gives hints to others (new workers) on how elderly have behaved after the medication or vice versa.

The participant mentioned documentation help nurses to evaluate the need of pain medication: “He got medication during/last weekend, should we need to give now or just observe him if that was just a temporary pain?”

Same participant mentioned that “we took pain medication out from the list of one elderly, because she was not feeling pain anymore, but it was not a good idea to take out the whole dose at once, because she started complaining about pain, so it would have been better to minimize the dose first and see how it was reacting with a smaller dose”.

Other participant mentioned the importance of documentation as well in prescribing pain medication in elderly care home. “During the doctor visit we (nurses) go through medication (that has already prescribed and ongoing) and check has it been enough or need to stop the dose, only after trying these we could be surer about their needs of pain medication.”

Yet another participant said that all behavioral changes should be written/documented. Because only written document is valuable to the physician for the further prescription.

The one participant mentioned that “it might sound funny but through patient’s document we could see that someday elderly have had medication five times in a day and some other day non. They believed that some are more sensitive about pain and offer more. It seems that various interpretation about pain create these kinds of results.” So, this participant believed that if elderly have had pain medication in ongoing (as a regular medication not just offer when needed) medication list with few doses that might reduce these kinds of results to occur in first hand. At least participant said “we can try and see”.

To explore it more, another view was like this: “if we start with small dose and you can see written document whether it has been helping enough or not, and if not then you can offer extra dose....”

Through the participants views/ experiences it seemed that documentation in pain assessment has not been as effective process in unit. As two participants mentioned “elderly get every day pain medication (in ongoing list), we assume it helps (enough), but don’t evaluate in time to time”.

Some of the participants had different thoughts about the matter of workload and its affects in documentation. These participants thought that workload with various reasons might hinder the documentation process. And on another hand, it could be because of unavailable staff in a shift or temporary staff not knowing the importance of documentation. Despite these facts some others believed that staff’s shortfall or lack of adequate time shouldn’t affect the regular and proper documentation for better pain assessment for example:

“Too much workload can affect to notice pain and their normal condition but if pain has already been noticed than workload shouldn’t affect in giving pain medication”. Another two participants have had a similar view: “ workload does not affect but pain could remain unnoticed”.

Through the participants ‘views, documentation could give various benefits in care unit. It gives staffs various ideas to handle various situations and different possibilities. As one participant said: “to make a peaceful good night sleep, we should give medication (if it’s written in documentation that person was having pain often and has been mostly restless during the night) because sleep disturbances also enhance pain”.

4.2.3 Communication as a Barrier in Pain Assessment

The majority of nurses described that pain is a subjective matter of fact. There were no ready measurement tools that could show a patient's volume of pain. They described that person's own word was more reliable. However, all the participants commonly agreed that persons with severe dementia could not express their pain through words. So only staff in care homes were the persons responsible and could assist with pain.

Although the participants mentioned that elderly's behavior attitude was hard to judge as a pain indicator unless there were some marks and signs, for example wound and other serious illness like cancer.

Like one participant said: "if we are knowledgeable about elderly's (nurse's referred particular patient) history of fracture, his hesitation for walking (unwilling nature), pain sensitivity (saying "auch!", refusing to hold hand) could have told us to understand that he is having pain, or he got pain when he walked or when we touched them"

Two participants shared similar views about concerning communication and behavior attitudes of an elderly with severe dementia. In their view, elderly lost the common words to express but they express with bodily language and other behavioral nature. For example: first view "through the restless behavior they are showing that they are not feeling comfortable or having pain, but as a regular worker or knowing elderly enough, you can distinguish whether it is normal or not" At another similar view "elderlies are more aggressive, distressed, sometimes they murmur, they talk nonstop, they might sing continually, but as a nurse we should know how to interpret these signs"

Many challenges have been discussed through the process. Different participants have had different views. One of the views was: "unlikely pain, like elderly can't say where exactly is hurting, but they only say that it's here or there, sometimes they just say they are feeling heartburn, but real pain could be the chest pain, so articulating right things the right way might have been challenging in assessing pain, rather than not being capable of speaking at all".

The other participant says, "during the care it's possible to notice the pain" but the great challenge is that "different people interpret pain differently". More precisely, "[a] person's own experience".

But most of the participants believed time limit, workload had been great challenge in pain

assessment process. As one participant mentioned “In ethics we should have time for them, but workload can [be] hindered.”

4.2.4 Importance of Pain Tools in Pain Assessment

Most participants realized that using pain tools and training would support for better pain assessment process. The participants were aware with numeric scales and visual analogue scales. But there were not any kinds of pain tools used in care systems. However, participants were not aware of other pain tools except VAS, which could be useful in this scenario.

The majority (all) of participants were well known about visual analogue scales but not aware with any other kind of pain tools. The newly graduated participants were also ignorant about the existence of pain tools other than numeric and facial tool.

One newly graduated staff nurse said “I only know numeric and facial scale tools. I don’t know other tools”. This was the same experience with other nurses as well, who didn’t know the different tools that were available, like Abbey pain tools, Doloplaus tools, and so on.

Most of the participants thought that a proper pain tool could be helpful in assessing pain among severe dementia elderly. They emphasized that related knowledge and education should be provided to staffs for better pain assessment. One experienced staff member said, “I am working in same field for ten years, never got any training/education” And “we are only using our limited knowledge”.

However, some of the participants regarded pain tool to be used on a regular basis but others seemed unsure if it even was going to work or not. They realized it would require more time to use pain tools. Two participants mentioned similar views that “pain tool should be very simple and easy to carry (pocket version), and not time consuming, otherwise it will just remain unused.” And other participants said that any kind of pain could be helpful in pain assessment.

For further details, one participant mentioned that “I would like to use a pain tool where elderly can’t express themselves or otherwise if it is difficult to interpret” The participant continued with saying that “in difficult situation, physician can prescribe pain medication in small dose and document well about its effectiveness, and then evaluate with the tool”.

For the last details, one participant pointed pain tool as better equipment for the irregular worker in the unit who does not know much about elderly.

In the end, most of the participants did realize that regular use of pain tool with new knowledge could be helpful for better pain assessment among elderly with severe dementia.

In a group discussion, as well as in the individual interviews the usefulness of pain tool was emphasized.

5 Discussion

The analysis data from face-to-face interview revealed facial expression as one of the most common pain assessment tools among severe dementia from nursing point of view. The group discussion as a second data did not provide any additional information for the researcher. However, it rather gave the influence of trustworthiness for the collected data.

Their views on assessing pain among severe dementia were condensed into eleven themes. Those themes were then divided into two categories like nurse's pain assessment approaches and factors that hinder pain assessment. Each theme has an interplay relationship with each other.

The nurses' perception on pain assessment seemed depended/influenced more on facial and bodily expression of an elderly with severe dementia. Whereas research says observational scales have some disadvantages like guarding, bracing, and moaning, which are also a typical behavior of dementia (Scherder et al., 2005).

In this research, behavioral approach as a pain assessment tool has not separately described/mentioned by the nurses. But it was rather considered as a progress of dementia symptoms by the participants than pain. Or it was simply said a difficult part to understand in advanced dementia. The decline of communication ability seemed to be a hindrance in pain assessment. So, in this research behavioral approach was described under the factor as communication barrier. One research has also emphasized that behavioral disturbances and mood changes have often been incorrectly judged as a dementing process and they often get prescribed with neuroleptic medication when the underlying cause of behavior is pain (Martin, 2005).

Of the all factors, education was highly expressed and agreed upon the importance by majority of the participants. The participants did not have any form of training related to pain assessment, as did not the newly graduated nurses.

In research, Patients with severe dementia require additional and necessary skills,

knowledge and even the expertise to enhance pain assessment process (Brown, 2011). It has clarified that only nurses' education and experiences do not only affect pain assessment but also influences the social context and general understanding among the staff inside the unit (Laurie, 2008).

The existing theory says that inevitable development in cognitive impairment in this type of disease, pain must be examined. The lack of knowledge about the effective pain assessment is not an important factor here, it also has side effects which play a crucial role in pain assessment. Like in Parkinson's disease, levodopa can provoke pain and burning paraesthesia (Scherder, 2005). This study encourages to be even more cautious about pain assessment not only concerning the medication prescribing, but also its possible effects which could cause even more pain.

The research has shown that nurses who work consistently with more experience with individuals with dementia, were more attentive and prone to assess (Burns, 2015). Although nurse's work experience was not well-studied in this project, except their working time period in dementia care unit. However, more work experienced ones shared more information during the interviews than the less experienced ones. More importantly, some shifts have only PN. This research showed PN roles in pain assessment are undoubtedly important where many PN spend more time in one shift than RN. It appears that most interviewed staff were willing to have more education/training related to pain assessment process. So, their knowledge required update concerning in pain assessment of severe dementia. Similarly, a study also emphasizes the need of continuing staff education for suitable assessment procedures (Martin, 2005).

The results showed documentation plays vital role in pain assessment. Furthermore, it also hinders pain assessment if the documentation was managed poorly. The general studies show the construction of pain documentation system and lack of systematic routines are other barriers for pain assessment in dementia care (Karlsson et al., 2012). So, the systematic pain assessment and management protocols have been found effective for residents with dementia that improve the management as well as minimize unnecessary polypharmacy in long term care. (Hadjistavropoulos et al., 2015).

In addition, as discussed/found in results, workload and different interpretation in pain assessment, change of staff, frequent changes of elderly's in unit, different understanding in

non-approaches pain assessment have had made pain assessment process difficult. And, all participants have had various knowledge and experiences (less or more) concerning pain assessment among severe dementia. However, nowadays nurses spend more time in administration than with patients on a daily basis, which has affected their pain assessment of dementia care (Karlsson et al., 2012). But the research showed that if there is good teamwork and communication between staff it does not need additional and separate reservation time in pain assessment process (Brorson et al., 2014; Cohen -Mansfield et al., 2005). As Herr et al., (2011) conclude, despite all hindrances in nursing assessment of pain among elderly, nurses have a moral and ethical obligation that must be advocated in professional level to make best pain relief possible. Although seniors (elderly) need more time to convey information about their pain, nurses mentioned how limited amount of time also influences pain assessment (Martin, 2005).

To overcome all those barriers gradually, pain management seems like one way for the better achievement of the area of pain assessment. By understanding these, using pain scale alone without its proper management would not be effective in the long term. The pain management helps to track the information about dementia in the elderly from the daily care perspectives and is easy to follow for new care givers. Pain tools give nurses the same interpretation possibilities, which aid the medical adviser (doctors) in medicine prescription.

Recent research has shown that pain assessment with close intervention has more positive influence than just regular assessment. The mandatory use of pain indicator tools in wards can make pain assessment policy systematic, rather than not using them (Douglas et al., 2016).

During this research process, pain tool was highly expected and felt as an obligatory tool for better pain assessment. But clinical utility and feasibility are also important for the acceptability of tools in clinical practices. Most of the studies lack sensitivity and specificity. Without these components, the scale is useless in clinical practice. Research has concluded that PACSLAC is appropriate for clinical use and psychometric properties. Scales cover both pain and behavioral problems (Zwakhalen et al., 2006).

Although PACSLAC tool has a long list as mentioned earlier, this could be good for a regular basis use. It is also helpful (having different properties) due to other reasons like different work experience background, frequent changes in elderly residents in ward, and frequent change of staff. Practically there are constant changes (frequent) of staffs as well in elderly residents.

In this scenario researcher believes that it will be helpful in assessment processes while it covers many areas of signs and symptoms.

6 Limitation

A limitation of the study could be the less vocal participants during the interview (face-to-face interview) process. But their shared knowledge had given the researcher a wider view for this research. However, face-to-face interview had given each interviewee independence and confidentiality to share their knowledge which could not have been possible in the group interview. As a matter of fact, during the group discussion as a second data, participants did not have any new views to add to the first set of interviews. So, could it be the case that they were more confident, and open about sharing knowledge and experience individually?

7 Conclusions and recommendation

In conclusion, the results help us to understand pain assessment process among severe dementia through nurses' limited knowledge, experience and available resources in the care unit. Nurses managed assessing pain if the elderly had physical defects (wound, fracture etc.) or chronic illness(cancer) that could refer changeable behavior as a pain indicator.

Pain assessment varies (varied) due to the individual interpretation. Even though the nurses' experience was not deeply researched, their shared knowledge showed that it had great influence in pain assessment. However, in practical contest, behavioral approach (it was concerned more as a progressive dementia behavior than a cause of pain) was dominated by the decline of the ability of communication of an elderly with severe dementia. Whereas nurses took poor communication as outmost barrier in pain assessment. The findings show that, each nurse has had knowledge on assessing pain. However, with the lack of evidence base knowledge, it was not cared holistically. some had used non -medical approaches and some others didn't mention it or used other approaches like medical approaches and so on. It seemed that each participant had had some good pain assessment approaches. But it was used individually and not as a regular process. However, as the nurses explained, pain assessment is hindered by shortfall of staff, workload, lack of training, absence of pain tool, lack of evaluation before and after pain medication etc.

This research suggests that there needs to be a change in systematic pain management to improve pain assessment. In practical basis, we need to have a close intervention to make better observation in pain assessment among elderly with severe dementia. Furthermore,

understanding their behavioral attitudes is not easy just through a single educational training. We believe that learning and educating is a continuing process, and it could be better if it happens through learning-by-doing. As mentioned, understanding severe dementia in elderly is complicated. Through a financial point of view as well, it is more economical to educate staff and let them educate the rest by following systematic pain management for example if a unit starts using pain tool with the pain management process, educated (who get training and education) ones can guide non-educated ones to use it. So, the researcher suggests two proposals, proposal one stands for PASCLAC tool (Appendix 2) and proposal two stands for how unit can use it or make it useful (Appendix 3). The researchers believe proposal two will lead nurses using pain tool (of course training is needed) in organized way to make better pain assessment. Allowing these, it will also help to get the information and improve the relationship between staff and the relatives. With the aid of proposal two, observation becomes long enough and could help nurses with better interpretation.

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Data Analysis

Meaning unit	Condensed meaning unit description close to the text	Condensed meaning unit interpretation of the underlying meaning	Sub-theme	Theme
I don't think education can solve pain assessment. Anyways, it's hard to recognize pain in non-verbal patients. Pain can only be identified by their subjective views.	<ul style="list-style-type: none"> • Education can't solve pain assessment • Hard to recognize in non-verbal residents • Applies subjective views 	<ul style="list-style-type: none"> • Pain is an individual experience • Education alone can't solve • Communication issue being subjective views 	Education alone not a solution in pain assessment of non-verbal patients.	Education role in pain assessment
I never had topic related education during my work experience (Majority of participants experienced). I believe that lack of knowledge on pain assessment makes difficult to recognize pain among severe Dementia.	<ul style="list-style-type: none"> • Lack of knowledge on pain assessment • Difficulty in recognition of pain 	<ul style="list-style-type: none"> • Inadequate knowledge / education in pain assessment. • Perception of pain 	Lack of education on pain assessment.	
If patients do not react in any situation like during care, no facial expression, no gestures. Especially in the terminal care (in a condition, like if they have cancer, or another	<ul style="list-style-type: none"> • Severe dementia elderly with terminal diseases hardly have facial or bodily expression, so offering pain medication could be humane. 	<ul style="list-style-type: none"> • Lack of bodily expression • Requirement of frequent pain medication 	Chronic disease with the lack of bodily expression required frequent pain medication.	Terminally ill patient with chronic disease routinely need

chronic disease) strong opioids should be given just to make sure that person is not suffering from pain.				
I believe that severe dementia patients should get pain medication sensitively (when they are dying) and who have been a bed patient for a while.	<ul style="list-style-type: none"> Severe elderly people with dementia should get pain medication herkästi 	<ul style="list-style-type: none"> Need of regular medication 	Regular pain medication	
During my long period of work experience, I realized that utilizing their relatives as an information provider like patient earlier behaviour or reaction towards pain could be one way.	<ul style="list-style-type: none"> Utilizing relative information in pain assessment is important 	<ul style="list-style-type: none"> The important of relatives' information 	Relatives' information	Relatives information as a work force
Sometimes relatives might not be willing to support and disclose all the patient's history, for whatever the reason behind.	<ul style="list-style-type: none"> Relative are unwilling share the information 	<ul style="list-style-type: none"> Unsupportive relatives' information disclosure 	Relatives' information	
Assessing pain in new patients is difficult. It becomes even more	<ul style="list-style-type: none"> Difficulty in assessing the pain among new elderly residents. 	<ul style="list-style-type: none"> New elderly residents. 	New residents	

difficult when we nurse have a lot to do, I mean work load.				
During the night shift, sometimes I offer drinks to patients. Sometimes it helps the elderly people's restlessness. So, I don't go for the pain medication immediately.	<ul style="list-style-type: none"> Offering drink reduces restlessness. 	<ul style="list-style-type: none"> Understanding individual's needs 	Knowing elderly's individual's needs	Knowledge on individual's needs.
When you do the two-three shift and you know the person for the long time you can see pain can disturb the sleeping habit that can influence a patient's mood.	<ul style="list-style-type: none"> Disturb sleeping habits influence elderly mood 	<ul style="list-style-type: none"> Elderly mood changes due to the sleeping disturbance. 	<ul style="list-style-type: none"> Sleeping disturbance and mood are co-related 	
I am more sure that restlessness can be the reason for bowel problems/incontinency rather than pain. This? Person is the example. I help her/him to the toilet when he/she becomes restless or even after they become aggressive. After helping, the patient becomes calm. Not everybody seems to	<ul style="list-style-type: none"> Bowel problems/incontinency sometimes leads to restlessness. 	<ul style="list-style-type: none"> View / understanding about the elderly's needs 	<ul style="list-style-type: none"> General needs / restlessness overall 	

understand this, especially when we have new care giver.				
With this elderly, I prefer taking care alone. When I am alone he/she is calm, we talk, everything goes well. But when he/she is with more than one care giver, she tries to kick. I don't know why but it could be that she likes my caring style or with many care givers at once she feels insecure or something along those lines.	<ul style="list-style-type: none"> • Taking care elderly alone rather with too many staffs. 	<ul style="list-style-type: none"> • Being in a pair makes patients uncomfortable • Being Insecure • Being ignorant 	<ul style="list-style-type: none"> • Being uncomfortable • Being irritate • Being ignorant 	

<p>It happens often that elderly come here without any medical report. We do not know their medical history, or the medication they have used (if any) (pain medication). It's impossible for nurses to assess pain in patients with cognitive impairment. To get the report is not always easy and fast, most of the times it is time consuming (when nurses have a heavy workload) when different sectors use different reporting systems. We do not have any other choice than to wait. Then both parties (patient and nurse) suffer.</p>	<ul style="list-style-type: none"> • Medical history and other diagnosed are the supportive role for pain assessment 	<ul style="list-style-type: none"> • Information on the medical history is crucial 	Medical records	Medical history in pain assessment
<p>In ethics, we should have time for them but still it is a major challenge that work load might affect pain assessment.</p>	<ul style="list-style-type: none"> • Workload affects pain assessment 	<ul style="list-style-type: none"> • Being overloaded • Being unable to provide full attention • Staff shortages 	Pain assessment under the work load	Lack of documentation effects in pain

In some existence importance of documentations is poor and for me in other way due to the various reasons like work load, frequent changes of patients affect the proper documentation.	<ul style="list-style-type: none"> Lack of Pain documentation effects in assessment which is time consuming 	<ul style="list-style-type: none"> Documentation is a time consuming 	Documentation effects due to the time limits	
I think terminal care with cognitively impaired patients with physiological changes like temperature and blood pressure rises could be the sign of pain. We mostly see this indicator as a reflection of pain.	<ul style="list-style-type: none"> Physical changes as a pain indicator 	<ul style="list-style-type: none"> Physiological 		Physiological changes as pain indicator.
Physical position of patient in bed should be comfortable (requires certain kind of pillow to keep changes the positions If the patient is incapable to move themselves) to avoid current or future sore pain. You see when we cannot change the position in needed way during the care time they became restless	<ul style="list-style-type: none"> Uncomfortable position in bed may create pain Requires comfortable position Provision of pillows 		Correct position Physical comfort	Non-medical approach

and they react with kicking. the pain might have developed being in same or uncomfortable position. If we do not consider these as a solution, we could easily say that it's psychological problems. We might sometimes mistreat the symptoms. What I mean here is unless we try things to solve we are never sure the exact reason behind pain.				
Nobody says to me to do so but I use different ways like massage and music to calm restless elderly patients. It helps them and they become calm for most of the time. But still it is hard to say what triggered a patient to experience pain and make him/her restless. Or he/she was just restless with other causes. But one thing I know is there is always possibilities of pain	<ul style="list-style-type: none"> • Massage and music comfort the elderly 	<ul style="list-style-type: none"> • Application of comforting measures 	<ul style="list-style-type: none"> • Consolation 	

when elderly have multiple diseases.				
<p>I used to know using numeric scale long time ago but not for the cognitively impaired patient. And I do not know any other scale that is for them.</p> <p>I recently graduate but don't know any scale except numeric and facial one. I do not have any experience using those.</p>	<ul style="list-style-type: none"> • Use of pain scales were none but having some knowledge on a vast and numeric scale 	<ul style="list-style-type: none"> • Lack of use of pain scales 		Pain tools in pain assessment

Even sometimes it is hard to say for us how much pain I have. It is difficult for nurses to say how much pain they (elderly) are having now when the elderly themselves cannot express themselves with words. In this scenario, one might say this much pain he/she has but another person could say different amount. Who to believe!	<ul style="list-style-type: none">• Communication is hindrance in effects in pain assessment	<ul style="list-style-type: none">• Communication deficiency takes place as a barrier in assessment• Poor communication hinders the assessment	<ul style="list-style-type: none">• Accuracy of pain assessment varies due to the lack of communication	Communication as a barrier in pain assessment
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Proposal 1

This is my recommendation as a proposal, not my creation.

Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Indicate with a checkmark, which of the items on the PACSLAC occurred during the period of interest. Scoring the sub-scales is derived by counting the checkmarks in each column. To generate a total pain sum all sub-scale totals.

Facial Expression	Present
Grimacing	
Sad look	
Tighter Face	
Dirty Look	
Change in Eyes (Squinting, dull, bright, increased eye movements)	
Frowning	
Pain Expression	
Grim Face	
Clenching Teeth	
Wincing	
Open Mouth	
Creasing Forehead	
Screwing Up Nose	

Activity/Body Movement	Present
Fidgeting	
Pulling Away	
Flinching	
Restless	
Pacing	
Wandering	
Trying to Leave	
Refusing to Move	
Thrashing	
Decreased Activity	
Refusing Medications	
Moving Slow	
Impulsive Behaviours (Repeat Movements)	
Uncooperative/Resistance to care	
Guarding Sore Area	
Touching/Holding Sore Area	
Limping	
Clenching Fist	
Going into Fetal Position	
Stiff/Rigid	

Social/Personality/Mood	Present
Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking).	
Verbal Aggression	
Not Wanting to be Touched	
Not Allowing People Near	
Angry/Mad	
Throwing Things	
Increased Confusion	
Anxious	
Upset	
Agitated	
Cranky/Irritable	
Frustrated	

Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)	Present
Pale Face	
Flushed, Red Face	
Teary Eyed	
Sweating	
Shaking/Trembling	
Cold Clammy	
Changes in Sleep Routine (Please circle 1 or 2) 1) Decreased Sleep ----- 2) Increased Sleep During the Day	
Changes in Appetite (Please circle 1 or 2) 1) Decreased Appetite ----- 2) Increased Appetite	
Screaming/Yelling	
Calling Out (i.e. for help)	
Crying	
A Specific Sound of Vocalization For pain "ow," "ouch"	
Moaning and groaning	
Mumbling	
Grunting	
Total Checklist Score	

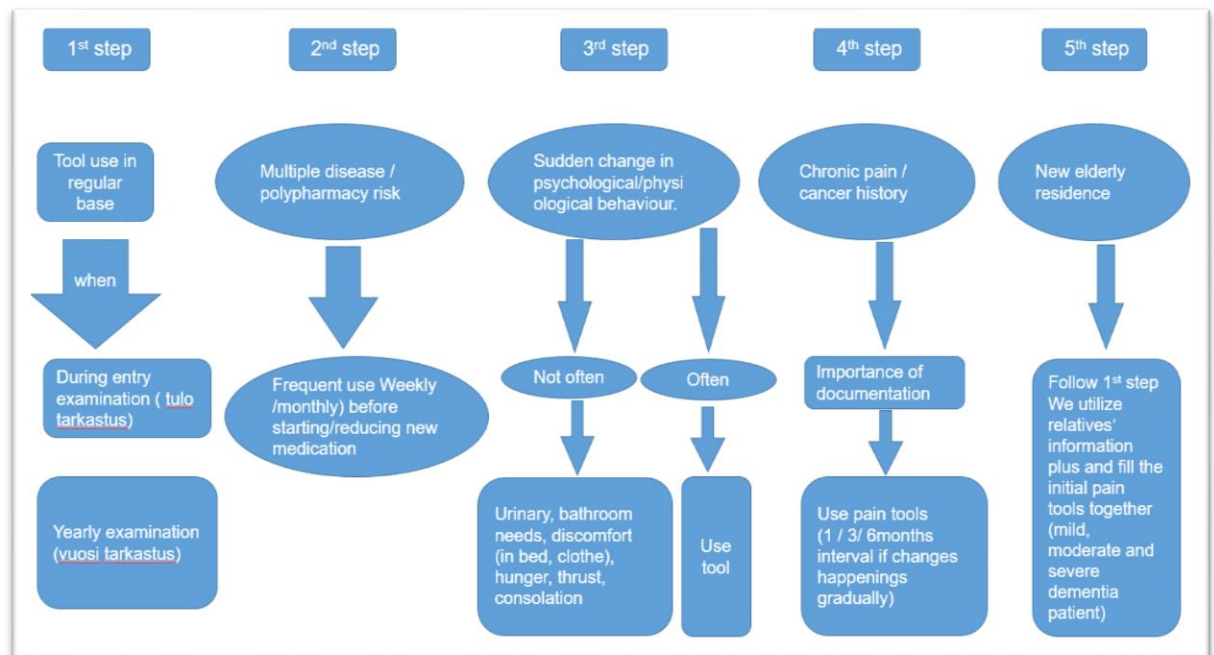
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References

Fuchs-Lacelle, S. & Hadjistavropoulos, T. (2004). Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing*, 5(1), 37-49.

Proposal 2 (Guidance for Systematic Use of Pain Tool)



Permission Letter

Pain Assessment in Severe (or advanced) Dementia:Nurse' role.

The purpose of the study is to find out how nurses assess pain in severely dementia elderly.

Qualitative research - Questionnaire and methods will be used to find the improvements in pain recognition and quality of care.

Approved to be conducted in Mainiovire, virekotimuurala, Espoo.

Signature by 
Jariina Pöyhönen
COO / MAINIO VIRE-OY